

*Title:* Access of WetAMD and DME patients to treatment  
in public hospitals

*Field of study:* Operations Management

*Purpose:* Dissertation for obtaining the Degree of Master in  
Business Administration (The Lisbon MBA  
International)

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## Acknowledgments

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This thesis would not have been possible without the sponsorship of Novartis, by sharing its experience in the treatment of WetAMD and DME in different world markets, and by providing access to leading Retina Specialists and Retina Service Directors of prominent national hospitals in Portugal.

I extend my deepest gratitude to Catarina Santos, Lucentis Senior Product Manager, for the support and guidance during the research, and for sharing her inspiring passionate belief in the treatment and protection of patients.

I also wish to thank Cristina Campos, Managing Director of Novartis Portugal, for promoting a sustainable close collaboration with The Lisbon MBA, and Cristina Morgado, at the time Novartis Ophthalmology Business Unit Head for supporting this project.

Likewise I would like to thank the dozens of doctors who have invested their personal time in my interviews, some taking 20 minutes in their office or in a storage room, others spending 2 hours in the hospital cafeteria, detailing their insights on the patient's pathway, and sharing their concerns for the patients and the resources they long for.

My homage to the albums *Delicate Sound Of Thunder* by Pink Floyd and *Master Of Puppets* by Metallica, for joining me on the four thousand kilometers I've spent on the road to interview physicians.

To my loving wife Filipa, for the affection and support during the MBA.

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## Abstract

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The objective of this investigation aimed at identifying ways of improving Wet Age-related Macular Degeneration (WetAMD) and Diabetic Macular Edema (DME) patients' access to treatment in public hospitals, by identifying bottlenecks and stress points that prevent timely and adequate care to patients who suffer from a degenerative disease, and consequently for whom the lack of access to treatment can have disastrous consequences.

Considering the specificity and degenerative traits of these conditions, the long queues for specialty appointments in public hospitals are a significant threat to patients' health, as the disease may be misdiagnosed and or progress significantly, causing unnecessary permanent and non-reversible loss in visual acuity.

Therefore optimizing the patient journey will increase patients' access to adequate treatment, and prevent avoidable progress of a degenerative condition which causes permanent and non-reversible blindness. Following the investigation which supports this thesis, the patient journey was broken down into its different phases, so that key issues could be identified, and referred back to the main stress points highlighted during the interviews with physicians and administrators.

Finally results were scrutinized and systematized, and a set of action points was proposed, considering what may cause major impact and is actually feasible to implement.

## Introduction

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WetAMD and DME are conditions of the retina, which progressively cause the loss of central vision. Exaggerated Vascular Endothelial Growth Factor (VEGF) cause new and abnormal blood vessels to grow behind the retina, often leaking plasma, causing displacement and damage of the retina.

Overexpression of VEGF in the case of WetAMD is caused by advanced age, most prevalent in patients over 60 years old, and in DME by the diabetic condition. The way vision is lost is distinct in both diseases, but both equally cause non reversible permanent blindness. Recent breakthroughs in science allowed for control of these illnesses, even though not achieving full reversal of the degenerative condition that would represent a cure, but still providing treatment as in a chronic disease.

The current medical protocol for treating these conditions recommends intravitreal injections with Ranibizumab and in some DME cases, supported by laser photocoagulation. Despite being a simple injection in the eye, with topic anaesthesia, intravitreal injections are surgical proceedings demanding an operating clean room with adequate medical teams, including a Retina Specialist physician.

The treatment protocol of WetAMD and DME recommends an initial loading dose of three monthly injections of Ranibizumab, followed by regular monitoring and injection whilst the visual acuity continues to improve.

Treating both Wet AMD and DME demands an adequate early diagnosis and follow up, which are the main significant challenges, given that most General Practitioners (GPs) are not fully trained for such specific conditions of the retina, and the queue for Ophthalmology specialty appointments in National Health Service (NHS) is measured in a matter of months.

Leaving an untreated patient with such a degenerative disease in the queue is tantamount to develop catastrophic consequences, possibly causing permanent blindness, with the inherent costs for the individual and the society. Such possibility is even more tragic, if demonstrated to have been avoidable upon timely and accurate diagnosis and treatment.

The investigation for this thesis was sponsored by Novartis, a global pharmaceutical company that commercializes Ranibizumab under the brand Lucentis. Novartis' pledge to the patients' health motivated the project, as an increase in efficiency in Retina Services would result in additional patients treated with the right therapy, at the right time, avoiding unnecessary progression of a degenerative disease. Novartis sponsorship did not condition research methods or findings for this master thesis. Its Managers were aware of the project from the start, and have not read, edited, suggested or hinted at any topics or conclusions for the drafts or for the final version of this document.

The research included interviews to Administrators, Ophthalmology Service Directors and Retina Specialists in public hospitals across the country, as well as discussions with GPs in order to grasp the upstream process. Whenever possible, data was collated from the hospitals' admin office in order to confirm data from multiple sources. In addition the investigation included interviews with Managers from Novartis on Marketing, Market Access and Regulatory, and Medical Affairs.

Main findings of this investigation concluded that:

- Non-medical acts are taken over by physicians due to lack of resources, which prevents them from being available for patients, which has an impact on the queue. *Flying nurses* could work as Clinical Secretaries, supporting different services, such as booking appointments, preparing the patient for exams, appointments and surgery. Plus currently emotional support is also currently provided by doctors. It is crucial to keep patients informed and engaged to follow treatment protocol and reduce attrition rates. *Flying nurses* could also educate patients on the disease, helping them to readjust their lives to reduced eye sight or blindness, and by providing emotional reassurance and counselling.
- Primary Care is the first triage and referral mechanism in the system. Despite the long queues for Hospital Ophthalmology appointments, the principle is not wrong. In order to provide greater support to GPs, a screening atlas, and the acute rapid access referral form could be implemented.
- Encourage informal referral networks by geographical area in order to provide training to GPs and simultaneously offer a communication channel to Primary Care to speed up first exams and treatment by Retina Specialists.
- Hold regular screening campaigns among the elderly for early detection of WetAMD.

Holding a discussion on the findings of this investigation, at a time of severe budget cuts, cutbacks in personnel and resources in the NHS is extremely important, as it is key to understand how it is possible to achieve more ambitious patient outcomes whilst controlling spending.

## State Of The Art

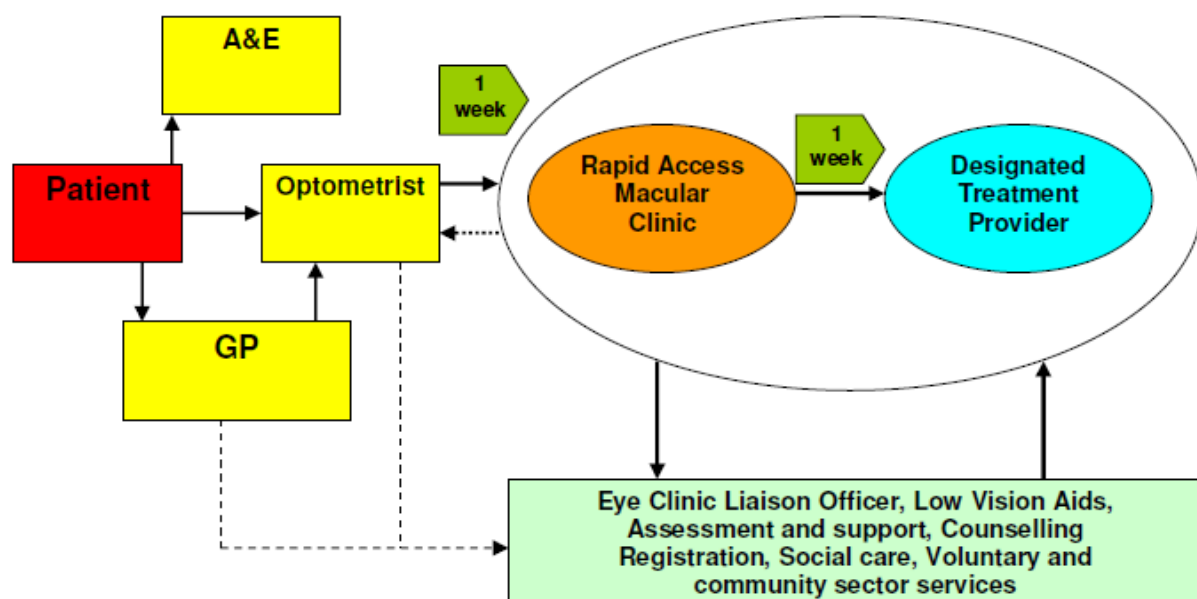
The literature on WetAMD and DME is vast, extending farther than the treatment with intravitreal injections, comprising the patient journey, direct and indirect costs, and the impact the disease and treatment has on patients.

### Patients' pathway

In 2007 the UK's Royal College of Ophthalmologists recommended one week maximum, as the time between referral and diagnosis in the treatment of WetAMD. In a study concluded that year, Cheshire and Merseyside county hospitals took on average a few weeks to do so, up to one month. WetAMD is an aggressive disease, much more than its *Dry* form, often causing sudden loss of visual acuity overnight, the leading cause for blindness in seniors in developed countries.

A report from the UK's NHS, established as priority to ensure a patient's pathway that would provide:

- A Primary Care setting where patients could go to address concerns for loss in visual acuity;
- Access to swift access to diagnosis and treatment;
- Emotional support, rehabilitation and access to social care.



*In the report "Age Related Macular Degeneration: Towards a strategy for the diagnosis, treatment and support of those with AMD in the Cheshire & Merseyside region"*



One of the conclusions of this study is that unsurprisingly, re-educating Primary Care professionals increased WetAMD referrals. It also increased false positives, but with a 75% true positives rate. It also recommended Primary Care to be more intervenient, holding more screening campaigns, supporting a sustainable preventive approach within the prevalent group.

An interesting recommendation is the screening atlas, and the acute rapid access referral form, which aim is to provide a guide for non Retina Specialists to hold screenings and to render a method for communicating findings in a structured manner that may quickly be interpreted and identify a possible positive.

The UK's NHS study identified resistance from ophthalmologists to work directly with optometrists (in Portugal these professionals are called orthoptists), preferring to liaise with the GPs, which are medical practitioners. This investigation encountered a similar resistance in Portugal, which is in fact a hindrance in the treatment as optometrists (in the UK, orthoptists in Portugal) handle OCTs and Angiographies, which are a fundamental phase of diagnosis and monitoring.

Macular Degeneration and Diabetic Macular Edema are two relatively unknown diseases of the general public, thus educating the population and raising its awareness should be a priority, particularly given that Diabetics patients often suffer from multiple infirmities well known to its patients and endocrinologists, which by itself enhances presentation and referral. Still WetAMD elderly patients are a vulnerable group, with attrition rates being influenced by mobility issues and the invasive nature of the treatment - intravitreal injections are in fact injections in the eye, which despite being done under topic anaesthesia, it still horrifies the faintest of heart.

Clinical trials and subsequent medical protocols average treatments taking around 2 years, comprising 8 injections, with 8 appointments, with at least 4 requiring an angiography. Such a heavy maintenance program naturally creates pressure in the NHS' resources. Not only for the treatment costs, but also because the Ophthalmology services may not be prepared to cope with demand, and the inherent pressure in the different stages of the patient journey.

A study for DME which included 345 patients around the globe in developed nations confirmed similarity of treatment, including a loading dose of three injections, followed by monthly shots or *PRN* (*pro re nata*), or as required, according to clinical evaluation, supported by exams such as OCT.

## Support to patients

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Several patients' associations and other organisations such as the Royal National Institute for the Blind, Macular Disease Society and Sight Savers provide emotional support, rehabilitation, low vision services and social care. The fact is that in advanced stages WetAMD and DME provoke permanent blindness, but in an earlier phase it

seriously affects central vision, which critically disrupts the ability to drive, read and even have a conversation without squinting.

The emotional impact of loss of vision is tremendous, severely affecting the quality of life, particularly for those living alone, with anxiety and depression often reported by AMD patients. Plus visual hallucinations caused by the Charles Bonnet syndrome, which is a pure visual effect, often cause aggravated distress on patients already in a terribly vulnerable position.

Such disturbance in lifestyle, affecting mobility and the way to interact with the rest of the world, triggering a sense of dependence from others, be it family or social services, is terribly unsettling emotionally, with depression rates among WetAMD patients growing up to 30%. There isn't much of a support structure for these patients in Portugal, with NHS struggling to address medical costs and resources alone. In 2007 the bill for health and social care in the UK rose to 63.5m GBP for WetAMD alone. A figure that does not include indirect costs, such as injuries or deaths related to lack of eyesight.

### Costs for society

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An observational study published in 2008 compared health care costs for the treatment of AMD from a societal perspective in Canada, France, Germany, Spain and the UK, concluding that in the 12 months prior to the study 12% to 22% of patients fell, with half requiring medical treatments. Additional spending other than direct medical treatment and exams included home care, visual aid equipment, counselling, rehabilitation, disability allowance, housing or other tax benefits, transportation for and from treatments, etc. Estimated total societal costs ranged from 671m EUR in Spain to 3.2b EUR in Germany. Therefore delaying the progress of the disease is likely to have an impact total spending.

Aging population in more developed countries presents a challenge for nationalized systems such as the ones of the UK and Portugal, as well as for their Health Authorities like NICE or Infarmed, by creating additional cost pressure in the national budgets. Therefore the cost-utility analysis has been gaining ground as a comparative tool for cost effectiveness. QALY (Quality Adjusted Life Year) is an indicator which aim is to provide a monetary value for quality of life gained, and therefore compare therapies and to establish thresholds. It has limitations considering the subjectivity on the notion of what perfect health is, or what parameters to use in its inputs. Plus ethical and political considerations may tip the scale beyond the numbers, for which patients' advocacy groups normally play an influential role.

However whereas the study by Hodge et al. on the Pharmacologic management of neovascular AMD from 2010 attributed a willingness to pay of \$50,000 per QALY, the Editorial of the Canadian Journal of Ophthalmology where this study was published, proposed a 16.2% return on investment on direct medical costs for the treatment



of AMD, and a net gain in GDP. The reasoning is improved vision allows for superior employability and salaries - such paradigm must also be taken into account when ascertaining the cost for society and the impact on the wealth of nations.

## Method

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The methodology for this thesis consisted primarily in breaking down the patient journey in its major phases, and to design a questionnaire for interviewing physicians that would be sufficiently detailed to allow exploring for inefficiencies, but simple enough to permit comparability between different hospitals.

Interviews to Retina Specialists and Service Directors in main public hospitals ensued, gathering information on the patient flow across the Ophthalmology Service. Such data was systematized and later segmented by hospital and issue type. That alone allowed identifying what were the recurring issues, granting greater credibility to those that kept arising in different locations.

The following physicians and administrators were interviewed:

- Dr. Manuel Mariano, Retina Specialist, Service Director and Board Member at Hospital Infante D. Pedro, Aveiro;
- Dr. Salgado Borges, Retina Service Director at Centro Hospitalar Entre Douro E Vouga, Santa Maria da Feira;
- Dr. Gil Calvão Santos, Retina Specialist at Centro Hospitalar Entre Douro E Vouga, Santa Maria da Feira;
- Dr. João Castro Sousa, Retina Specislist and Acting Service Director at Hospital de Santo André, Leiria;
- Dr. Neves Martins, Retina Service Director at Hospital Pedro Hispano, Matosinhos;
- Dr. Carla Teixeira, Retina Specialist at Hospital Pedro Hispano, Matosinhos;
- Dr. Joaquim Canelas, Retina Specialist and Head of Retina Services at Centro Hospitalar Lisboa Norte Santa Maria;
- Dr. David Martins, Retina Service Director at Hospital de São Bernardo, Setúbal;
- Dr. Margarida Santos, Retina Specialist at Hospital de São Bernardo, Setúbal;
- Dr. Mário Pires, Retina Specialist at Hospital Nossa Senhora do Rosário, Barreiro;
- Dr. Luísa Coutinho dos Santos, Administrator at Instituto de Oftalmologia Dr. Gama Pinto, Lisbon.

During this process, referral from Primary Care arose as a critical point in the overall treatment. Therefore discussions with GPs were added to the investigation in order to grasp the drivers for early (eventual mis)diagnosis and follow up by Retina Specialists. The following GPs were interviewed:

- Dr. Marta Cardoso, General Practitioner at Primary Care Unit Sete Rios, Lisbon;
- Dr. Neto Rodrigues, General Practitioner at Primary Care Unit Matosinhos;
- Dr. Margarida Miranda, General Practitioner at Primary Care Unit Leça da Palmeira;
- Dr. Olga Araújo, General Practitioner at Primary Care Unit Mozelos;
- Dr. Isabel Nazaré, General Practitioner at Primary Care Unit Mozelos;
- Dr. Erpídio Canastro, General Practitioner at Primary Care Unit São João de Ver.

Novartis was fundamental by providing the global experience, and how treatment of WetAMD and DME has been progressing in different countries. In addition their knowledge of the NHS and the hardships of different ophthalmology services, along with their support on treatment protocols of WetAMD and DME, provided a structural guidance for the elaboration of the questionnaire. Finally Novartis' influence was decisive for gaining access to physicians and administrators. Main sponsorship was provided by:

- Catarina Santos, Senior Product Manager Lucentis;
- António Vanzeller, Key Account Specialist Ophthalmology;
- Carlos Atílio, Key Account Specialist Ophthalmology;
- Francisco Guerra, Key Account Specialist Ophthalmology;
- Sofia Ferreira, Key Account Specialist Ophthalmology;
- Ana Luísa Paupério, Medical Science Liaison Ophthalmology;
- Joana Mesquita, Medical Science Liaison Ophthalmology;
- Teresa Guerreiro, Senior Market Access Manager.

Towards the end of the investigation phase a couple of interviews was setup with the Private Sector. After gathering so much information about the stress points of the Patient Journey in the Public setting, it was interesting to compare if the drivers of access were similar in Private. Two physicians of the SAMS hospital were interviewed for this purpose:

- Dr. Pedro Cruz, Ophthalmology Coordinator at SAMS Hospital, Lisbon;
- Dr. Rui Costa Pereira, Retina Specialist at SAMS Hospital, Lisbon.

During The Lisbon MBA 2012, Universidade Católica's Professor Miguel Gouveia, Hospital Da Luz's Administrator Pedro Líbano Monteiro and former Health Minister Maria de Belém Roseira were interviewed for a project for the Consulting Lab Course. Considering the value of these interviews on the NHS from a macro perspective, some of its content was also considered upon the elaboration of this thesis.

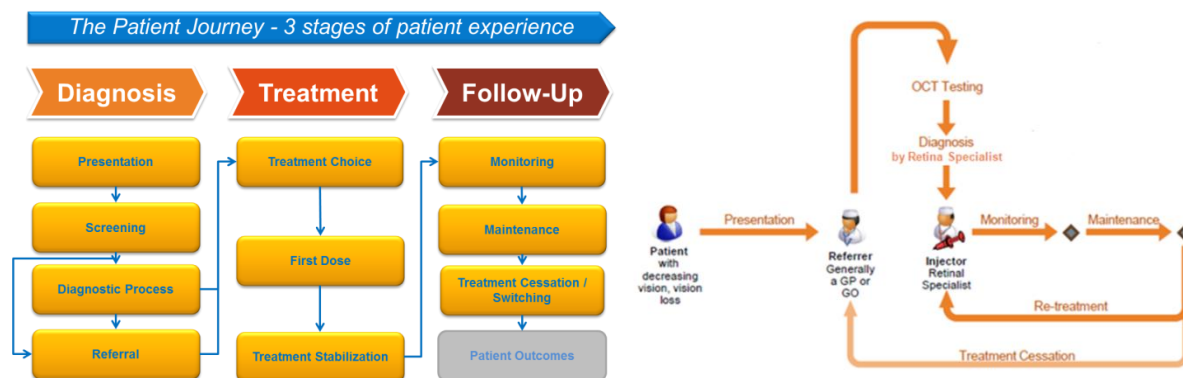
## Results

The field work combined with literature on the treatment of WetAMD and DME provided significant insights on the level of access of patients. The most efficient way to analyse stress points and potential improvements, is by detailing the Patient Journey in order to understand decision making steps and possible solutions to issues.

### The Patient Journey

The Patient Journey is a process map that details different steps and stages of the treatment, from early diagnosis to patient discharge. Its aim is to breakdown each phase in order to understand the requirements and stress points on each stage.

For WetAMD and DME, the Patient Journey can be detailed as follows:



Considering the investigation for this thesis, relevant keynotes from each phase are as follows:

#### i. *Presentation*

WetAMD patients' access to treatment in public hospitals is normally routed through the GP, to the Ophthalmology specialty appointments, although in theory it is also possible for a patient to voluntarily show up in ER, for instance in the case of sudden loss of eyesight overnight, or being referred by a Private Ophthalmologist, depending on hospitals' policy. Whereas DME patients mostly arrive from diabetic follow up and GPs, as Ophthalmological reviews are standard protocol in supporting diabetic patients.

The presentation phase is critical as it will determine patients' priority. Primary Care is the main triage and referral mechanism in the NHS, therefore it is crucial that GPs are aware of the symptoms of WetAMD and DME, and are prepared to perform a crude early diagnosis, knowing that at least an OCT is required for an accurate assessment. 4 of the 6 GPs interviewed for this thesis were not fully aware of how to diagnose WetAMD or DME, requiring further guidelines, and simply refer vision impairments to the GO (General Ophthalmologist) through the Alert system, an online referral tool to forward patients to nearby hospitals

## ii. *Screening*

Monitoring patients preventively is standard in the follow up of Diabetics. Side effects are well known by the medical community and the population at large, so it's customary procedure to perform regular eye exams to prevent DME or Diabetic Retinopathy.

Notwithstanding there isn't a national program, as in the UK, the NHS Diabetic Eye Screening Program, and patients have to rely on their GP or on the Diabetic service of their local hospital to program such screenings for them.

From the visited hospitals only Feira seems to have an agreed program with a body overseen by the Health Authorities - ARS Norte (Administração Regional de Saúde) for preventing screening of diabetics. Often the list of patients overlaps with those already being followed at the hospital, which is a waste of resources, since the same patients are screened twice. But at least these are being monitored.

Even though the prevalence of Diabetes is rising due to change in lifestyle, people are better informed, with easy access to literature. Conversely potential WetAMD patients are less protected given that the prevalence group is older, often less informed and with greater difficulties of access to medical care. Plus, the level of awareness within the medical community on Primary Care is not at the level of Diabetology. There are a few screening programs to monitor for WetAMD, done in Primary Care units and advertised at micro level in local communities, such as senior centres and local districts such as the *Juntas de Freguesia*. But often these are privately funded and one-off in time, lacking the sustainability of a long term program, properly shared with the community as the one from UK's NHS.

## iii. *Diagnostic*

For a proper diagnosis an OCT (Optical Coherence Tomography) scanner is required, following the dilatation of the eye. It's a process that requires time, resources and qualified professionals. And it's

one of the reasons GPs don't perform it at the Primary Care setting, as often they have a waiting room full of patients, and even if they had an available OCT, which is a very expensive equipment, they probably wouldn't know what to look for, as most are not trained on the subject.

For a more complete diagnosis, some Retina Specialists order a contrast Angiography, which reveals blood vessels in a more evident manner. However such exam is cumbersome as it involves preparation, with the assistance of a nurse to inject the contrast agent and the X-Ray equipment to gather the images.

But often, the OCT is sufficient for Retina Specialists to perform an accurate diagnosis. And the more experienced Orthoptists the technicians that perform the OCTs, know how to recognize a possible WetAMD or DME during an exam, and refer it immediately to the Retina Specialists, speeding up the diagnostic process.

Some hospitals have queues for exams, but all claim to prioritize critical patients. The diagnostic process is pressured both by new patients and maintenance, as the ones under treatment require regular exams to monitor progression of the disease. However, in order to meet demand for OCTs, some technicians give up on some basic tests, such as the Snellen Eye Chart, which later has to be performed by physicians. Notwithstanding some of the Ophthalmologists supporting hospital appointments are also Retina Specialists, which saves the extra step of referral to a specialist and further wait for exams.

#### *iv. Referral*

All visited hospitals demonstrated serious issues in addressing demand to initial Ophthalmology appointments, best case being Aveiro with 2.5 to 3 months queue, and worst being Leiria with 8 months queue for a first Ophthalmology appointment, to which is necessary adding an initial queue to visit the GP in Primary Care.

The Alert system is an online workflow tool used by GPs in Primary Care for referral to the hospital's GO appointment. The Retina Service will then perform a triage of the referred cases, according to the description provided by the GP. The purpose is to manage the queue, assigning priority to urgent cases, typically the ones of children, diabetics, and previous cases of WetAMD. Still the GP may always refer the patient directly to the ER, instead of the GO.

Insufficient time, resources and experience with WetAMD and DME by GPs may lead to under diagnosis, not providing enough detail for physicians at the hospital to know the full extent of pathology. Such risk is higher in WetAMD, since normally mentioning "diabetic" combined with "loss of vision" is sufficient for hospital physicians to assign priority to such patients.



The Alert system is the driver for positioning patients in the queue for a GO hospital appointment, and the reasoning presented by the physician will determine if a patient will have priority or is placed at the end of the queue. Therefore it is crucial that GPs know when they are facing a degenerative disease that may cause permanent blindness and state it so when referring the patient for appointment with a GO.

v. *Treatment Choice*

The state of the art recommends patients with WetAMD and DME to be treated with intravitreal injections of Ranibizumab. But increasing pressure to cut costs has been a strong motivator to use Bevacizumab instead, a molecule used in the treatment of colon cancer, but considerably less expensive. Additionally vial split of Bevacizumab is a common practice, therefore reducing significantly the cost per dose, but still keeping full financing from ARS, which is provided by treatment, not on the product itself. Thus using Bevacizumab is actually a source of additional financing for hospitals.

Both Ranibizumab and Bevacizumab derive from the same molecule, and target unwanted VEGF, which is actually a mean for tumours to grow and spread in the body. However Ranibizumab is an Ophthalmological product and stays in the eye, whereas bevacizumab spreads through the body, potentially leading to the unwanted close down of other blood vessels and arteries, causing thrombosis, leading to heart attacks or strokes.

vi. *First Dose*

Most Retina Specialists use a loading dose of three monthly injections to initiate the treatment. Often OCT exams are performed during the initial stage to monitor if the patient is responsive to the treatment. But it also happens, particularly in backed up hospitals, for patients to receive the loading dose of three injections before going back to an appointment with a Retina Specialist or to an OCT exam.

It is also frequent in DME for Retina Specialists to ignore the loading dose and follow *PRN* (*pro re nata*), or as required. Meaning that an OCT exam is performed to test progression of visual acuity, and then decide if the patient should receive an injection.

In urgent cases, despite queues, Retina Specialists try to squeeze in critical patients for injection. The same logic applies to diagnostic exams.

**vii. Treatment Stabilization**

Medical protocols recommend monthly appointments and injections until visual acuity stabilizes. In DME laser technology is also used combined with Ranibizumab.

**viii. Monitoring**

Monitoring of WetAMD and DME requires a monthly OCT to evaluate progress of visual acuity. However the monitoring of existing patients reduces availability for first appointments. Retina Specialists who handle themselves the booking of appointments and exams for their patients, have to spend such time on admin tasks, which could be used to see and treat patients.

**ix. Maintenance**

The treatment of WetAMD and DME requires monthly injections of Ranibizumab. Patients will continue in the system whilst their visual acuity responds, and even after that, they will return for monitoring every 3, 6 or 12 months. The need to continually review patients creates a cumulative effect in the system, locking new patients out, contributing for the staggering month long queues for the first appointment.

The need to cut corners to speed up processes leads to inefficient decision making, as such:

- Some hospitals often perform a 2<sup>nd</sup> loading dose on new patients if they respond to the first one (3+3). Due to lack of time patients are only monitored after the 3<sup>rd</sup> and 6<sup>th</sup> injections.
- Sometimes patients are returned to the GO, due to lack of time for proper follow up, but knowing that they will be sent straight back to Retina Services. Emotional support to patients is very important, considering the psychological impact of near blindness in advanced age in the case of WetAMD, thus it is vital that they feel they are being followed by physicians. But such action, besides not adding any value, creates additional pressure on the GO appointment, which already faces a queue of months.
- Some Orthoptists leave the Snellen Eye Chart test behind in order to meet demand on more complex exams like OCTs or Angiographies. However such basic and simple tests have to be done nonetheless, and end up being performed by the physicians later, and consequently adding further delay on the queue.

Physicians spend considerable part of their time on non-added value tasks, pushing basic and admin chores up the value chain. Physicians should not be performing non-medical acts, as other professionals cannot do what only they can.

*x. Treatment Cessation*

The treatment will stop following the stabilization of the patients' visual acuity. WetAMD and DME patients are in fact bearers of a chronic disease, being reevaluated after ceasing injections 3 to 6 months or 1 year later.

Still, a patient that does not show up for treatment in a public hospital is not contacted to reschedule. This is an important insight, particularly for WetAMD, whose elderly patients may need a more personalized support, especially given the impact that loss of eye sight may have on the quality of life at an advanced age.

## Main findings at visited hospitals

Queues	Feira	Matosinhos	Leiria	Setúbal	CHLN	Aveiro
GO first appointment	5 months	5 months	8 months	5 months	6 months	2.5/3 months
RS first appointment	1 week to 4 months	1 week	1 week	4 to 6 months	1 month	1 to 2 weeks
First exams	4 months Angiography; OCT same day	Same day	1 week	1 month Angiography; OCT same day	Same day	Same day
First injection	1 week	1.5 months	1 week	1 month	1 week	1 week
Periodicity	Monthly	Monthly	Monthly	Monthly	4 weeks	Monthly
End   Return after	1 year	1 year	6 months to 1 year	3 months to 1 year	3 to 6 months	3 months to 1 year

Main issues	Feira	Matosinhos	Leiria	Setúbal	CHLN	Aveiro
Long queues for first GO appointment						
Non-medical acts; admin tasks						
Angiography 4 months queue	Lack of physicians					Larger coverage, queues growing
OR not fully utilized	1.5 months for first injection			OR not fully utilized		Orthoptists not doing Snellen test, RS does it
		No resources for preventive screening				

The first thing that strikes out from the collected data is the staggering waiting times for first GO appointment. Such long times (e.g. 8 months in Leiria) was the original motivator to investigate the Referral process upstream with GPs, given the catastrophic consequences an under diagnose may have.

The pressure on Retina Specialists in these hospitals is intense, with some of them showing clear signs of exhaustion and stress. A physician shared that after a Retina Specialist leaving the service, no replacement was recruited, patients were simply distributed. This RS got the first of these patients 8 months after their original physician had left, at which time there was little that could be done, as the disease had progressed significantly in some of the patients. This physician was interviewed in August 2012, and shared that back in May all appointments for the year of 2012 were already fully booked.

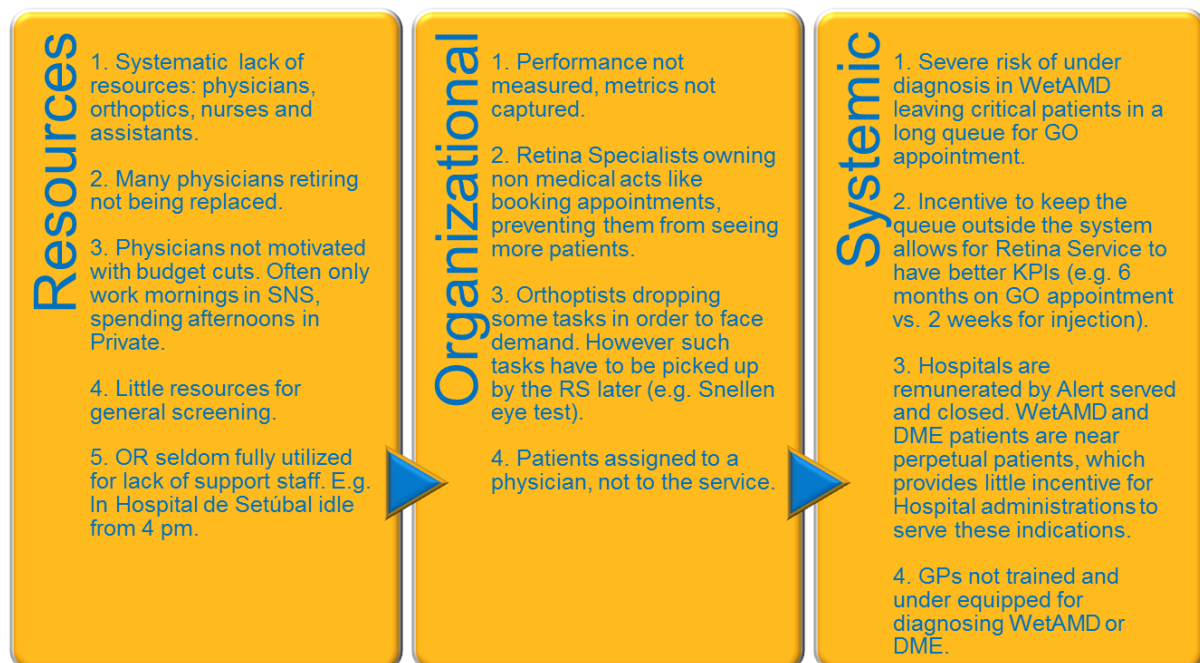
Ranibizumab is a biological product, and its injections have to be provided under a surgical environment, which demands an Operating Room (OR) and supporting staff of two nurses (prep and recovery) and a couple of assistants. However it often happens for both the RS and the OR to be available to inject (with the OR idle from 4 pm), but no intravitreal injections being done for lack of surgical support team.

Retina Services in which the RS has to handle admin tasks, like booking appointments, are far less productive than those where there is a clinical secretary to handle it. Such insight is not only common sense but actually verified with numbers. One RS that worked in two different hospitals treated almost twice the patients (32/33 vs. 16/17 patients per day) in a service with a clinical secretary that handled all bookings of appointments and exams. In an interview with Pedro Líbano Monteiro, the Administrator of Hospital Da Luz, from the private group BES Saúde, shared that it took them only a year to realize how powerful can be the role of a Clinical Secretary, as it unlocks most of the value of physicians, by allowing them to concentrate on the medical acts and specialized knowledge.

Hospital Da Luz also employs Appointment Assistants, who manage the waiting room in specialty appointments, prepare the room and the patient before the physician arrives, who actually moves from office to office. This different approach to the traditional Doctor's office allows significant time saving, removing the wait for the patient to get from the waiting room until settling down in the office. Otolaryngologist Mário Andrea uses this approach in his private practice, even taking it to the next level, with more junior physicians making the initial assessment and observation of patients, with him observing the patient only at the end, and spending 5 to 10 minutes only with each straight forward case. The philosophy is to enter only to add value. Similarly to what Partners in Audit and Consulting firms do, dedicating only a few of their hours per average size client. Clinical Secretaries can work in a surgical environment, and in addition to handling admin, they can also assist the RS to take notes

## Frequent capacity issues

Most frequent capacity issues found can be categorized by type, allowing understanding with deeper discernment the root of the problems. Conceptually issues can be then characterized as of Resources, Organizational and Systemic.



It's striking how the capacity issues at hand are so seriously affecting patients' outcomes, much more than the choice of therapy itself. Considering that budget cuts in NHS are unavoidable, it is imperative to make the most of available resources, which includes managing the queue for first appointment superbly well.

## Recommendations

Given that Presentation and Referral are key milestones in the Patient's Journey, it is paramount that its drivers are well under control. Since Primary Care plays a major role in how patients get into the queue, it is necessary to educate Health Care Professionals (HCP) at this level, and provide them with the tools that allow for an early diagnose, and render them the possibility for educating the population and hold regular screening campaigns with risk groups, such as diabetics and elderly patients.



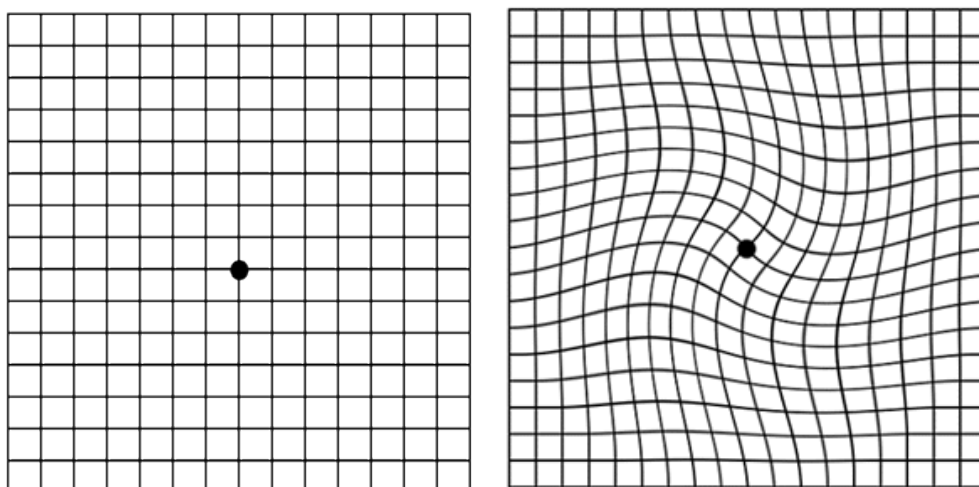
*i. Flying nurses*

Considering the dramatic impact that Clinical Secretaries have in the number of patients seen and treated, but in order not to overburden hospitals' costs, a flying nurse would be suitable solution to support the service of different hospitals within a geographic area, supporting Ophthalmology services in the booking of appointments and exams, in addition to following up on patients who don't show up to treatment, encouraging them not to abandon the therapy.

Plus patients do need a positive factor to keep them engaged and stopping them from lapsing into anxiety and distress states. They will be able to deal with their emotions better if a nurse can spend time with them addressing their concerns and fears.

*ii. Local referral network*

Creating a local referral network between Primary Care and the local hospital would help to raise awareness with GPs, and also provide them with contacts they could use in order to advise the hospital when they suspected of a case of WetAMD or DME. This genuine approach is used in Germany and in Italy, and it works simply by bringing a Retina Specialist to the Primary Care unit to lecture GPs for 45 minutes, possibly during their weekly clinical meeting, this way avoiding dragging GPs to cumbersome congresses that remove them from supporting their patients and family life. Providing GPs with a screening atlas and an acute rapid access referral form, along with Amsler grids would allow for additional simple tools that may make a dramatic difference in the life of patients a few months later.



*An Amsler Grid allows for the patients to self-test. If a patient sees the squares or the black dot squinting they should look for a Retina Specialist immediately.*

### *iii. Regular screening for WetAMD*

Whereas diabetics are offered regular eye screening for DME and Diabetic Retinopathy, there isn't a structured assessment for WetAMD, which leaves the elderly, a more vulnerable and less informed group, farther exposed. It is necessary to provide more information to communities, especially in senior centres and community groups.

Using voluntary work and applying for sponsorship from the private sector may fund regular screenings in the local hospitals, utilizing existing OCT equipment. The most expensive in a screening is the reading of the exams, for which is needed a Retina Specialist.

#### Drivers of access: Public vs Private

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Whereas Retina Services in NHS struggle to cope with excess demand, in Private the financing is driver for access. As any specialty drug such as Oncology, HIV or Rheumatoid Arthritis, treatments with Ranibizumab are expensive, and only a fringe of the population can afford them out of pocket. Nonetheless an insurance with reasonable coverage or a public subsystem like ADSE will provide significant financing, enough to make the copay affordable. For private clinics, maintenance of WetAMD and DME is as a source of business, and therefore they have the incentive to ensure patients follow up clinical recommended protocols. So unsurprisingly there is adequate follow up of patients, making sure they come to appointments, exams and injections.

Nonetheless regardless of the incentives, concern for patients' health exist both in private and public setting, with Retina Specialists focused on protecting patients

## Conclusion

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Whilst waiting for a physician to finish an appointment, so I could hold an interview, I have witnessed what I interpreted for a patient being diagnosed with DME - a lady in her fifties, joined by her daughter. Both looked absolutely desperate with the prospect of irreversibility of the already lost eyesight, and it was the Retina Specialist who was trying to calm them down and maintain a pragmatic approach in scheduling an urgent injection for that week, to try to contain the progression of the disease. The emotional support recommended by the UK's NHS, in Portugal ends up by being done physicians themselves, when they should be free to see more patients.

In recent years possibly there hasn't been a single issue of economics newspapers without relevant news on the NHS and the effort for controlling its costs. Trimming back has been seriously impacting capacity by cutting back personnel across the board (physicians, nurses, technicians and assistants). Considering the absolute imperative that is to have an NHS that is sustainable, nonetheless an important insight is that it is not possible to manage a service or a hospital by decree. Therefore by imposing cutbacks, frailties and system bottlenecks become even more evident. Which stresses even more the need to manage the Patient Journey and its queues. Particularly because WetAMD and DME have a cumulative effect, with maintenance adding pressure to the system. However gaining capacity and increasing productivity will result in increased expenditure in treatment costs, which is the exact opposite of hospital Administrations' objectives these days.

The issues revolving around the treatment of WetAMD and DME raise an important discussion on what kind of society we want to have. Especially because the Portuguese population is aging, and it's absolutely frightening to grow old alone and unprotected. This is a provocative ethical issue which is at the foundations of the current and future NHS. Whether we keep the current Beveridge Model, adopt a different philosophy along the lines of the Bismack Model, or even hold a hybrid standard, it is important that the discussion happens openly and the society has the opportunity to convey its opinion and have a say on what kind of future we'll leave to our children.

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